



## The Journey from Struggle to Strength From the Director

*By Tonia Ferguson*

Throughout the nation, parents of children with autism and other developmental disabilities face many struggles navigating the array of information and service systems available to them. For those who have just learned that their infant or toddler has special needs, the questions of when and where to begin these processes, who to contact, and whether services are available in their community can be overwhelming.

Parents whose children are already in the school system may well be aware of Individuals with Disabilities Education Act (IDEA), a federal law that provides special education for all children with disabilities. Yet they also may have many questions. For years, I have heard about families struggling through the special education maze. Because of the many intricacies of the special education process and occasional difficulties with working with individual teachers and districts to ensure that their children are getting the best service and education possible, many parents often feel confused, frustrated,

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### News Items

['Eye on the door': Life with autism wandering](#)

Whether it's to a swimming pool or a doughnut store, Michael Browne knows where he wants to go -- and since he doesn't have the words to say so, he'll just dart off.

[College Addresses Autistic Students' Struggles](#)

In many ways, Mark Heim is a typical senior at Colorado State University. He has the kind of smart humor you'd expect from someone who excels in computer science, engineering and math; his T-shirt reads, "Department of Redundancy Department." But as a student living with Asperger's syndrome, a high-functioning form of autism, the everyday social interactions of college

perplexed, and generally lost in the system.

One thing that I have learned as a parent is that it is critical for any parent to be as informed and savvy as possible in order to negotiate these mazes of services and systems. Each family needs to become an expert at navigating the system and knowing your and your children's rights in order to move from stumbling through a maze of systems to taking a leadership role in your child's services.

Recently, the Center received a call from a parent who was preparing for her first transition planning meeting. In this conversation, this parent said, "I just don't feel empowered to advocate at my meeting.... Will my daughter have a job when she graduates? Are there laws that guarantee her services and benefits as an adult?"

The Center directed this parent to our Autism NOW website - [www.autismnow.org](http://www.autismnow.org). This website is a critical tool through which Autism NOW provides families, people on the spectrum, and professionals resources and information on issues across a lifespan that are relevant to people with autism and other developmental disabilities.

After several days, we heard back from that parent. After visiting the Autism NOW website, this parent told us, "I feel empowered NOW!"

While we here at Autism NOW provide insight into the many entry points, rules and regulations, and strategies and best practices for accessing and navigating of the maze of systems and services, the central goal for why we are here is for you and your journey from struggle to strength. We are here to empower YOU to make the best decisions for yourself and for your family.

life can be awkward.

#### [Adults with autism look to make lives for themselves](#)

For a few months, Myles King had his dream job. It was one of only a few employment opportunities he's ever gotten. "He had a great piano gig at a restaurant downtown for nine months. And they closed up and didn't bother to call anybody," said Myles' mother Tree King. At 20 years old, Myles is a 2008 graduate of South High School and a piano player who has already released an album. However, every accomplishment has been made more difficult by the fact that he has autism.

## **Intensive, Week-long Leadership Institutes**

This week-long, intensive leadership development program is designed for current executive-level leaders and emerging leaders. Participants may work in areas of management or program leadership in organizations that provide, advocate for, or fund supports for people with intellectual/developmental disabilities and their families.

The focus of the Leadership

So, visit [www.autismnow.org](http://www.autismnow.org). You, empowered!

# National Advisory Committee Update

## From the Co-Director

*By Paula C. Durbin-Westby*

On March 16, 2011, Autism NOW chaired the first meeting of the National Advisory Committee. The National Advisory Committee is made up of people who identify as having a disability, parents, and other stakeholders, including researchers, educators and other professionals. One of the ongoing tasks of the National Advisory Committee is to assist with selecting and reviewing materials for the Autism NOW website. At our first meeting, the National Advisory Committee talked about selection criteria for materials and discussed the concept of evidence-based research. Then, the National Advisory Committee formed a subcommittee to decide on the selection criteria process for website materials. Based upon this criteria process, the National Advisory Committee will be quite active in overseeing current website features and materials. Autism NOW and the National Advisory Committee have already started using this criteria process to determine which new resources and information will go on the website; so check back to the website regularly to see new resources and materials that we have added!

One important part of all National Advisory Committee meetings is having access to communication that benefits all committee members. All National Advisory Committees feature CART, Communication Access Real-time Translation. This service means that meetings are held over the phone and online at the same time. A person

Institute is on assessing and strengthening leadership skills, setting organizational direction, and understanding the future of the intellectual/developmental disabilities field. Institute participants come away with demonstrated leadership ability and a firm grasp of the skills and values critical for quality, individualized supports.

Participants will learn the skills needed to:

- Succeed in leadership challenges unique to the developmental disabilities field today;
- Manage and sustain person-centered, values-based transformational change;
- Build and sustain positive organizational culture at all levels.
- Challenge the status quo through risk-taking; and,
- Set and achieve ambitious goals for yourself and your organization.

[Learn more and apply now.](#)

trained in CART listens to the phone call and types in everything that is being said on the phone almost as fast as it is said. So, National Advisory Committee members can see the words online. Also, there is also a chat room for people to use if they communicate in writing instead of through the phone. After the meeting, both the transcript of the phone call and the chat room are sent to everyone on the call so that all National Advisory Committee members can know what has been said during the meeting. In general, National Advisory Committee members have made positive comments about the communication arrangements and have participated in survey that will make future meetings even more accessible. [Find out more about CART.](#)

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## Calendar of Events

[Full Calendar Listing](#)

### Upcoming Webinars The Medical Home and Early Intervention

Tuesday, April 26, from 2:00 to 3:00 PM EST

The Autism Program of Illinois will be presenting a webinar describing and defining the medical home and the impact of family advocacy to enhance early interventions for children with autism spectrum disorders.

## Resource Spotlight

With the launch of the new Autism NOW website on April 1st, the resources provided by the Center have become more diverse. This Resources Spotlight highlights two resources from our new website and from our webinars that you should check out!

### The Catalyst Center

[www.catalystctr.org](http://www.catalystctr.org)

Funded by the Maternal

## Partner Updates

### Archived Webinars on Medicaid Home and Community-Based Services

The Friday Morning Collaborative is a coalition of national aging and disability organizations working together to protect and strengthen Medicaid Home and Community Based Services (HCBS). With support from The SCAN Foundation, the coalition is hosting a series of webinars to

Space is limited.

[Reserve your seat now.](#)

**Celebrating the Autism  
Community with Asperger  
Adults of Greater  
Washington**

Thursday, April 28, from  
2:00 to 3:00 PM EST  
Asperger Adults of Greater  
Washington will be joining  
the Autism NOW Center to  
discuss its work as a social  
and support groups for  
people with autism  
spectrum disorders in the  
greater Washington area.

Space is limited.

[Reserve your seat now.](#)

**Upcoming  
Conferences/Summits  
Autism NOW Regional  
Summit: Prince George's  
County, Maryland**

Saturday and Sunday, May  
14 and May 15

This event will include  
opportunities for  
relationship-building  
between stakeholders,  
families, and people who  
identify as having an autism  
spectrum disorder or  
intellectual/developmental  
disability; for sharing

and Child Health  
Bureau and a project of  
the Boston University  
School of Public Health,  
this Center conducts  
policy research to  
identify and evaluate  
financing innovations;  
creates resources about  
health insurance and  
financing for all children  
and youth with special  
health care needs;  
provides technical  
assistance on health  
care financing policy  
and practices; and  
connects those  
interested in working  
together to address  
complex financing  
issues. This  
organization presented  
a webinar on Health  
Insurance Options for  
Children with Autism  
Spectrum Disorders,  
which provided  
information about the  
health insurance  
prevalence for children  
with autism spectrum  
disorders and their  
families. This webinar  
also provided  
information about state  
autism waivers as well

provide information and  
resources that may  
assist state advocates  
in preventing cuts to  
HCBS, while promoting  
the adoption of new  
options in the Affordable  
Care Act. Below is a list  
of archived webinars.

**Budgets: Challenges  
and Opportunities for  
Home and Community  
Based Services**

February 25, 2011

Speakers:

Judy Solomon (Center  
on Budget and Policy  
Priorities)

Wendy Fox-Grage  
(AARP Public Policy  
Institute)

Jerry Reilly (Eldercare  
Alliance –Washington  
State)

Diane Justice (National  
Academy for State  
Health Policy)

[Archive of the webinar.](#)

**Cost-Effectiveness of  
Home and Community  
Based Services**

March 25, 2011

Speakers:

Stephen Kaye (Center  
for Personal Assistance

information and resources; and for celebrating the local and regional autism and intellectual/developmental disability community.

[Apply to attend this Regional Summit.](#)

For further information, please go to our [page about Regional Summits.](#)

**American Association on Intellectual and Developmental Disabilities: National Convention in The Twin Cities, Minnesota**

Monday to Thursday, June 6 to June 9

The AAIDD 135th Annual Meeting, Inclusive Communities: Pathways to Realizing the Vision, will provide leading practitioners, researchers, teaching faculty, policymakers, funders, and advocates with effective and emerging practices, cutting edge research, and valuable information on important policy initiatives.

[Learn more about this conference.](#)

as the Combating Autism Act.

To find out more about the Center, please go to: [www.catalystctr.org.](http://www.catalystctr.org)

[View the Catalyst Center's Autism NOW webinar.](#)

**National Secondary Transition Technical Assistance Center (NSTTAC) Video Resources: Writing Postsecondary Goals**  
([www.nsttac.org/](http://www.nsttac.org/))

The National Secondary Transition Technical Assistance Center ( NSTTAC ) helps states build capacity to support and improve transition planning, services, and outcomes for youth with disabilities. This particular [web-link connects you to an online activity](#) that provides people who identify themselves on the autism spectrum another opportunity to think about what they want to do after they finish high school. This activity includes an

Services, University of California San Francisco)  
Lisa Alecxi (The Lewin Group)  
K. Charlie Lakin (Research and Training Center on Community Living, University of Minnesota)  
Dee Mahan (Families USA)  
[Archive of webinar.](#)

employment and post-secondary goal worksheet and an online tutorial to support the person on the spectrum in completing the activity.

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